

Mental Disorders Caregiver Burden and Stress during Covid-19 Pandemic

Rindayati Rindayati^{1*}, Ah Yusuf², Nisa K. Illahiati³

1. Nursing Doctoral Study Program, Faculty of Nursing, Airlangga University Surabaya Indonesia.
2. Faculty of Nursing Airlangga University Surabaya Indonesia.
3. Communication Department Faculty of Social and Political Sciences Airlangga University Surabaya.

Abstract

This study explored the burden and stress of caregivers who take care for patients with mental disorders during the Covid-19 pandemic. A caregiver is considered one of the family members who cared for families with mental disorders but also experienced burdens and stress, especially during the Covid-19 pandemic.

This research used qualitative approach with interpretive phenomenology as paradigm. Held in December 2020-January 2021, a sample of 12 informants was selected by purposive sampling, criteria included having experience caring for patients a healthy, voluntary informant, and able to describe their experiences well. The research instrument used in-depth interviews. Data were analyzed by maintaining the authenticity of phenomena, investigating experiences, reflecting on essential themes, and describing and rewriting phenomena.

This study resulted in three themes representing the burden and stress of caregivers in caring for patients with mental disorders during the Covid-19 pandemic: behavior as a stressor, the economic burden of the Covid-19 pandemic, and symptoms of perceived stress. Conclusion: The Covid-19 pandemic affected the burden and stress of caregivers who cared for schizophrenia patients beyond the usual situation. Therefore, this study implicated that caregivers for mental disorders need the knowledge to understand and manage their stress and burden.

Clinical article (J Int Dent Med Res 2021; 14(3): 1224-1229)

Keywords: caregiver, burden, stress, mental disorder, Covid-19.

Received date: 19 January 2021

Accept date: 06 August 2021

Introduction

Caregivers who care for patients with mental disorders in the Covid-19 pandemic era experience greater burdens and stress than in the previous period¹. Covid-19 has caused job losses, fears of contagion, and decreased income². This condition affects the cost of living, the cost of care and environmental stigma, which can be a caregiver for burdens³. Inappropriate coping strategies can have an effect on stress, manifesting in physical conditions such as muscle tension, headaches and psychological problems such as inability to focus to sleep disturbances^{4,5}. Research in England and Spain

informs that the Covid-19 pandemic has an impact on caregiver mental health problems such as burden and stress⁶. It appears that caregivers who are under stress with all the symptoms can effect carrying out treatment, which has an impact on recurrence⁷.

According to previous research, the pandemic has caused more stress and burden to individuals, let alone caregivers who have the responsibility to take care of mental disorder patients⁷. This is the central problem of this research. So, the problem statement for this research is what kind of burden and stress are added to caregiver's experience in taking care of mental disorder patients during the Covid-19 pandemic? In order to come up with a solution, it is important to examine the description of the caregiver's burden and stress during the Covid-19 pandemic.

The prevalence of patients with mental disorders in the world reaches 20 million patients⁸. During the Covid-19 pandemic, patients with mental disorders are more prone to relapse⁹.

*Corresponding author:

Rindayati Rindayati,
Nursing Doctoral Study Program, Faculty of Nursing, Airlangga
University Surabaya Indonesia.
E-mail: rindayati-2019@fkn.unair.ac.id,
rindayati@vokasi.unair.ac.id

Research in East Java has informed that 46% of patients with mental disorders relapse 1-3 times a year and sometimes a little more than three times a year¹⁰. Data at the Gresik Health Office show the number of patients with mental disorders continues to increase. So, the scale of research is in Gresik Region, East Java, Indonesia within the December 2020 to January 2021 period.

The burden and stress of caregivers in the Covid-19 pandemic era includes patients' aggressive behavior that threatens the safety of themselves, their family and the environment and which becomes a burden for the caregiver. The decline in income during the Covid-19 pandemic era affects medical costs, transportation to health services and the daily cost of living for patients¹¹. Patients with mental disorders have a higher risk of contracting Covid-19 than patients in general¹². This burden can play a role in triggering stress. Research has found that most caregivers experience stress that manifests physically and psychologically, such as difficulty sleeping, chest palpitations, anxiety, and even embarrassment to interact with other patients¹³. Caregivers who are under moderate to severe stress, are unable to treat optimally and eventually the patient relapses¹⁴. Recurrence has an impact on increasing the burden objectively and subjectively to the caregiver¹⁵.

The role of caregivers during the Covid-19 pandemic is very much needed, so support to build positive coping and nurse education in stress management is very helpful in reducing caregiver burden and stress¹⁶. The results showed that stress management skills training contributed significantly to improving psychological wellbeing¹⁷. Based on the research and scientific reasons stated earlier, the study took the title "Mental Disorders Caregiver Burden and Stress during the Covid-19 Pandemic". Based on those arguments, finding a solution to ease caregiver's burden and stress while caring for mental disorder patients, describing its experience, which identified specified themes during the pandemic, is crucial. In conclusion, the state of art of this research is describing basic data of caregiver's burden and stress experience according to themes during the Covid-19 pandemic.

Materials and methods

This study used a qualitative design with an interpretive phenomenology paradigm in accordance with Heidegger's key principles¹⁸. The target population in this study was caregivers who cared for patients with mental disorders in the Gresik region detected for as many as 1342 patients. The sample was selected by purposive sampling, which involved informants who met the predetermined criteria according to the saturation or redundancy conditions¹⁹. The 12 informants met the criteria of: having experience caring for patients with mental disorders during the Covid-19 pandemic, physiologically and psychologically healthy, being voluntary participants as evidenced by signing informed consent, and being able to tell their experiences well.

The research instrument used researchers themselves, in-depth interview guidelines, field notes and cell phones as recorders and field notes. The data collection procedure used in-depth interview as a process of digging into and exploring in-depth experiences by asking participants directly to reveal new information about the burdens and stress experienced while caring for patients with mental disorders during the Covid-19 pandemic²⁰. Data collection was carried out by visiting the participants' homes then explaining the research objectives, signing the agreement, time contracts, explaining ethics and confidentiality, then conducting an interview for approximately one hour for each informant.

Data analysis is based on Van Manen (1990) by maintaining the authenticity of phenomena, investigating experiences based on phenomena, reflecting on essential themes that are characteristic of a phenomenon, and describing as well as examining the phenomena. Ethical clearance for this research has been carried out by following research principles and has received approval from the informants.

Results

Based on in-depth interviews with 12 informants, the data identified three main themes of burden and stress experienced by caregivers while caring for mental disorders patients during the Covid-19 pandemic, namely patient's behavior as added stressor, economic burden

during the Covid-19 pandemic identified by symptoms of stress that manifested into caregiver's experience as described below.

The first theme is patient's behavior as stressor with the sub-themes of violent behavior and strange behavior. Most of the participants said that, at the beginning of illness, patients with mental disorders engaged in violent behavior. Violent behavior harms other patients and the environment, which makes the caregiver depressed. Several participants described violent behavior that became a stressor, as follows:

"He once climbed into a tree with hot coffee ... when a person rides a motorbike under it, he keeps pouring ... yes the person gets angry." (P2)

The next violent behavior that can become a stressor is verbal and non-verbal behavior. Verbal behavior by patients with mental disorders is painful and frightening. There were participants who said that the patient was angry and said hurtful words, someone asked to be called a genie because he said he was disturbed by a genie. Another participant said that, when the medicine runs out, the patient gets angry with the neighbors, so that the caregiver feels embarrassed and depressed. Participants described the following:

"If they are angry, they get scolded, medeni (scary) ... I give two drugs, it doesn't work ..." (P4, P5, P12).

The next stressor is obtained from the strange behavior of patients with mental disorders, such as that displayed physically and makes the caregiver confused, sad, and worried. Behaviors such as a patient immediately approaching when he saw girls wearing shorts and then taking off his pants is very embarrassing and makes the caregiver worry about the future of the patient they care for. A confused caregiver approached the police to ask for help to keep his younger brother safe from the wrath of the community. Another strange behavior was told by the prostrate prayer participants, not getting up until their bodies were stiff and difficult to move. This strange behavior as a stressor was told by the participants as follows:

"He once walked in front of a shop, kept seeing girls wearing shorts in the shop, he was immediately approached and immediately removed his pants." (P7)

The participant's strange behavior as a

stressor influence was reported by the participant in that if her child said something strange, that she was pregnant, but she said she was not pregnant, so her husband returned home to be cared for by his mother. Participants were confused and more confused after giving birth to their children when speaking in Indonesian. Participants told the following:

"Niku's thoughts are weird (which they think makes no sense), they say weird speeches (they speak unnaturally), when they are pregnant, they say they are not pregnant ..." P10.

The various behaviors of patients with mental disorders described above are stressors for caregivers, especially during the Covid-19 pandemic where the emotions of patients with mental disorders become more sensitive.

The second theme engages with economy. Three sub-themes were found on the burden experienced by caregivers in caring for patients with mental disorders during the Covid-19 pandemic, namely decreased income, medical expenses and daily living costs. The social distancing policy as an effort to prevent the transmission of Covid-19 has an impact on various sectors of life. This expense was reported by several participants who experienced a decrease in sales or a loss of income.

"His father works as a fisherman, but since the Covid incident no one has invited him to sail." (P12)

The cost of treatment during the Covid-19 pandemic is also a burden for caregivers, where, before the pandemic, drugs were given free of charge from the puskesmas, but, during the pandemic, they were ordered to buy them at personal cost. Another participant said that, even though their child's medicine was given free of charge by the puskesmas, they still needed transportation costs. Another participant told about the need for fees to pay to physicians. In a sad tone, a participant said:

"The medicine now has to be bought at the pharmacy, but before the same doctor gave a prescription." (P11)

Other burdens come from daily living expenses. During the Covid-19 pandemic, patients had to stay at home more. So they needed more food and drink needs. Patients with mental disorders said that their siblings asked for snacks continuously, so that they used up a lot of money for snacks. Another participant said that

his nephew is sick when he consumes food on the table, even though all the family has not eaten.

"All food is spent, even though the others have not eaten, for example being kicked out ... where did this Andri go, clerical lak (vagrant)." (P11)

The story above was told by several participants who described the economic burden of the Covid-19 pandemic as a trigger for stress for caregivers.

The third theme is the emergence of stress symptoms that are felt by caregivers found in two sub-themes, namely psychological and physiological symptoms. Psychological symptoms include feeling tired, unable to sleep for a month and even feeling crazy. Participants described their psychological feelings.

"I have not been able to sleep for a month ... I said ... I am iki (I'm also mentally ill)." (P12)

Some of the physical symptoms which appear in the form of dizziness, abdominal pain, muscle aches, increased blood pressure and blood sugar also often increase. The story was told by the following participant:

"Yes, sometimes if you feel dizzy drinking bodrex ... if you have a stomachache drink Promag my bones here (pointing at the legs) also often hurt." (P9)

The limitations of this study are scale of study as it was located in Gresik Region, East Java, Indonesia within December 2020 to January 2021 period with three themes that identified burden and stress of caregivers' experience.

Discussion

The results are discussed in detail not only from the interpretation of the researcher, but complemented by theories related to the literature on the results of previous studies in the hope that the results obtained are more accurate.

The results of the study inform that the burden and stress of the participants begins with the behavior as a stressor. Stressor is caused from violent behavior and strange behavior of patient with mental disorders. Violent behavior, both verbally and non-verbally, such as getting angry, grumbling, disobeying, and doing whatever you want can be a stressor. Violent behavior that is considered the most stressor is

dousing patients with hot coffee, and grumbling angrily to the caring mother. Patient behavior that challenges verbally and non-verbally causes the caregiver to be sad and emotional²¹. The behavior of patients with mental disorders has a psychological impact on the caregiver, who is a family member²².

The strange behavior of patients with mental disorders, such as prostration during prayer, not getting up until the body is stiff and being pregnant but saying that they are not pregnant can be a stressor. The strange behavior that is most regarded as a stressor is to finish eating alone food that is served for the whole family, a patients coming up to girls and immediately removing his pants, and running to the upper house and wanting to jump. Caregivers who witness this strange and worrying behavior have psychological and physiological effects²³. Caregivers caring for patients with psychiatric problems experience moderate to severe stress related to initial disease behavior and patient relationships¹⁴.

This study further found that the economic burden during the Covid-19 pandemic experienced by caregivers who cared for patients with mental disorders resulted in a decrease in income, medical expenses and the cost of daily life. Decreased income, such as selling less rice, or herbal medicine is an economic burden during the Covid-19 pandemic. Meanwhile, the burden felt the most significant was sailors who were not invited to go fishing, which was their main source of income. Social distancing policies to prevent Covid-19 transmission limit the space for workers to move. Many workers who need interaction in carrying out their work have lost their jobs in various sectors since the Covid-19 pandemic²⁴. The negative impact of the Covid-19 pandemic on the level of economic activity is very significant and puts an economic burden on families that can create tension²⁵.

The burden in the form of medical expenses requires buying medicine at the pharmacy with personal money, which was previously given by the health center and was felt by the caregiver as an additional burden during the pandemic. The economy during the pandemic, which has experienced a decline, coupled with an increase in spending on drug purchases, increases the burden on caregivers. The impact of the Covid-19 pandemic on the economy in Indonesia affects various sectors,

such as transportation, health and others, but the impact on the economic sector is most pronounced in the household sector²⁶.

The cost of everyday life in the form of patients with mental disorders asking for snacks continuously because of having to stay at home is a burden during the Covid-19 pandemic. However, by staying at home with patients with mental disorders always eating food without giving a rest to other family members is a heavier burden. The Covid-19 pandemic is a public health challenge that has a devastating impact on household economies. An online survey of 17 countries in Latin America and the Caribbean shows that the economic impact is very large, where one member of the household reported losing his job and another closing his business²⁷.

The stress symptoms felt by participants while treating patients with mental disorders during the Covid-19 pandemic were found to be psychological and physiological. Psychological symptoms are in the form of feelings that appear as feeling tired of caring for and having not been able to sleep for a month and even feeling that they are also crazy, which shows the level of stress he is suffering. This is influenced by the social distancing policy during the Covid-19 pandemic, as caregivers stay at home with patients with mental disorders who are being treated longer, so that the length of caring for them is longer. The length of time caring for patients with mental disorders can affect the level of burden experienced, and cause psychological symptoms³. Stress exposure results in sleep disorders, such as difficulty sleeping, as well as a drastic decrease in sleep quality when stressed²⁸.

Stress that is manifested physically is a complaint in the body in the form of frequent headaches, stomach aches, increased blood pressure and muscle aches. The stress that comes from the behavior of patients with mental disorders, plus the economic burden of the Covid-19 pandemic, causes caregivers to fall under stressful conditions. The results of the study indicate that the manifestation of stress can occur physically and mentally, in the form of headaches, abdominal pain, muscle tension, even insomnia, so that the caregiver is unable to treat and the patient relapses⁵. Changes in daily life, caring for the sick and acculturation-adaptation processes were identified as sources of stress. Caregivers who experience stress

suffer anxiety problems and physical complaints such as nausea and headaches.

Conclusions

In conclusion, the Covid-19 pandemic adds burden and stress, such as changing of mental disorder patients' behavior because of limited outdoor activity, adding stress to the caregiver. Moreover, increased needs that are not met with more income also include more burdens to them. Also, these burdens and stress are manifested into their experiences caring for mental disorder patients'. So, this study implicated that caregivers for mental disorder patients need the knowledge to understand and manage their stress and burden.

Acknowledgements

The author would like to thank the Dean of the Faculty of Nursing and the Head of the Gresik District Health Office for the research permission granted.

Declaration of Interest

The author has no interest and conflict with any party in the implementation of the research carried out in the preparation of the article.

References

1. Sheth K., Lorig K., Stewart A., Parodi JF., Ritter PL. Effects of COVID-19 on Informal Caregivers and the Development and Validation of a Scale in English and Spanish to Measure the Impact of COVID-19 on Caregivers. *J Appl Gerontol.* 2021;40(3):235-43.
2. Enriquez D., Goldstein A. COVID-19's Socioeconomic Impact on Low-Income Benefit Recipients: Early Evidence from Tracking Surveys. *Socius.* 2020;6(1):1-17.
3. Gabriel IO., Aluko JO., Okeme MI., Israel C., Gabriel O., Aluko O., et al. Caregiver Burden Among Informal Caregivers of Women with Breast Cancer. 2019:11384-92.
4. Bademli K., Lök N. Feelings, thoughts and experiences of caregivers of patients with schizophrenia. *Int J Soc Psychiatry.* 2020;66(5):452-9.
5. Chiu MYL., Wei GFW., Lee S., Choovanichvong S., Wong FHT. Empowering caregivers: Impact analysis of FamilyLink Education Programme (FLEP) in Hong Kong, Taipei and Bangkok. *Int J Soc Psychiatry.* 2013;59(1):28-39.
6. Lynch A., Bastiampillai T., Dhillon R. Can COVID-19-related anxiety trigger a relapse of schizophrenia? *Aust N Z J Psychiatry.* 2020; 18(3):954564.
7. Hasan A., Musleh M. The impact of an empowerment intervention on people with schizophrenia: Results of a randomized controlled trial. *Int J Soc Psychiatry.* 2017;63(3):212-23.
8. WHO. Schizophrenia 4. 2021;(October 2019):2019-22.
9. Kementerian Kesehatan RI. Laporan Riset Kesehatan Dasar 2018. *Lap Nas Riset Kesehatan Dasar.* 2018;53(9):181-222.

10. Fitriyasaki R., Nursalam N., Yusuf A., Hargono R., Chan C-M. Predictors of Family Stress in Taking Care of Patients with Schizophrenia. *J Ners*. 2018;13(1):72.
11. Ilmy SK., Noorhamdani N., Windarwati HD. Family Burden of Schizophrenia in Pasung During COVID-19 Pandemic: A Scoping Review. *Indones Nurs J Educ Clin*. 2020;5(2):185.
12. Wu YH., Sun FK., Lee PY. Family caregivers' lived experiences of caring for epidermolysis bullosa patients: A phenomenological study. *J Clin Nurs*. 2020;29(9-10):1552-60.
13. Wan K., Wong MMC. Stress and burden faced by family caregivers of people with schizophrenia and early psychosis in Hong Kong. 2019;49:9-15.
14. Darlami K., Ponnose R., Jose P. CAREGIVER ' S STRESS OF PSYCHIATRIC PATIENTS. 2015;03(02):39-43.
15. Lippi G. Schizophrenia in a member of the family: Burden, expressed emotion and addressing the needs of the whole family. *South African J Psychiatry*. 2016;22(1):1-7.
16. Hawken T., Turner-Cobb J., Barnett J. Coping and adjustment in caregivers: A systematic review. *Heal Psychol Open*. 2018;5(2), 1-10.
17. Alborzkouh P., Nabati M., Zainali M., Abed Y., Shahgholy Ghahfarokhi F. A review of the effectiveness of stress management skills training on academic vitality and psychological well-being of college students. *J Med Life*. 2015;8(Spec Iss 4):39-44.
18. Horrigan-Kelly M., Millar M., Dowling M. Understanding the Key Tenets of Heidegger's Philosophy for Interpretive Phenomenological Research. *Int J Qual Methods*. 2016;15(1):1-8.
19. Alfiyanti Y., Rachmawati IN. Metodologi Penelitian Kualitatif dalam Riset Keperawatan. 1.a edición. Jakarta: PT. Raja Grafindo Persada; 2014. 20-24.
20. Ishtiaq M. Book Review Creswell, J. W. (2014). *Research Design: Qualitative, Quantitative and Mixed Methods Approaches* (4th ed.). Thousand Oaks, CA: Sage. *English Lang Teach*. 2019;12(5):40.
21. Hansen BR., Hodgson NA., Budhathoki C., Gitlin LN. Caregiver Reactions to Aggressive Behaviors in Persons With Dementia in a Diverse, Community-Dwelling Sample. *J Appl Gerontol*. 2020;39(1):50-61.
22. Azman A., Jamir Singh PS., Sulaiman J. The mentally ill and their impact on family caregivers: A qualitative case study. *Int Soc Work*. 2019;62(1):461-71.
23. Wang M., Wang F. Awareness , Utilization and In uencing Factors of Social Support for Main Informal Caregivers of Schizophrenia Patients: A Cross-sectional Study In Primary Care Settings In Beijing , China. 2020. *BMC Family Practice*. 2020. 21(192): 1-8.
24. Koren M., Pető R. Business disruptions from social distancing. *PLoS One*. 2020;15(9 September):1-14.
25. Varona L., Gonzales JR. Dynamics of the impact of COVID-19 on the economic activity of Peru. *PLoS One*. 2021;16(1 January):1-16.
26. Susilawati S., Falefi R., Purwoko A. Impact of COVID-19's Pandemic on the Economy of Indonesia. *Budapest Int Res Critics Inst Humanit Soc Sci*. 2020;3(2):1147-56.
27. Bottan N., Hoffmann B., Vera-Cossio D. The unequal impact of the coronavirus pandemic: Evidence from seventeen developing countries. *PLoS One*. 2020;15(10 October):1-5.
28. Kalmbach DA., Anderson JR., Drake CL., Hospital HF. Vulnerability To Insomnia and Circadian Disorders. 2020;27(6):1-39.